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Discharge of breast cancer patients to primary care at the end of hospital follow-up: A cross-sectional survey

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KEYWORDS
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Abstract ***Aim:*** The present study explored (a) the discharge of breast cancer patients to primary care by specialists, at the end of hospital follow-up and (b) the experiences and views of general practitioners (GPs) regarding transfer of follow-up to the primary care setting.

Methods: A cross-sectional survey was performed by sending a self-administered questionnaire to 960 GPs working in the three northern provinces of the Netherlands. Data were analysed using descriptive statistics.

Results: Of 949 eligible questionnaires, 502 were returned, providing an adjusted response rate of 53%. In the year before the survey took place, one or more patients aged >60 years, and 5 years after breast-conserving therapy, were discharged to 22% of GPs ($n = 112$) for follow-up. According to 56% of these GPs, transfer of follow-up was communicated by the hospital. The initiative to arrange follow-up visits and mammography appointments was mainly taken by patients. In this survey, 40% of GPs ($n = 200$) were willing to accept exclusive responsibility for follow-up earlier than 5 years after completion of active treatment. Perceived barriers in current and future primary care-based follow-up included: communication with breast cancer specialists, patients' preference for specialist follow-up, GPs' oncology knowledge and skills and the organisation of follow-up in general practice.

Conclusions: Primary care-based follow-up might be improved if breast cancer specialists discharge patients more actively to their GPs. Survivorship care plans are needed to facilitate communication across the primary/secondary interface and with patients. Training of GPs and developing administrative tools may be helpful in arranging follow-up care and using guidelines in general practice.

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1. Introduction

After primary treatment for breast cancer, follow-up examinations in the hospital are common practice. The aims of follow-up are to detect recurrences at an early stage, to evaluate and monitor side-effects of treatments and to provide physical and psychosocial rehabilitation.[1,2] Several guidelines exist for follow-up.[3–5] In the Netherlands, the current breast cancer guidelines recommend hospital follow-up for 5 years, including yearly mammography. After these 5 years, patients aged >60 years, and treated with breast-conserving therapy, are discharged to their general practitioner (GP) for yearly physical examination and two-yearly mammography. Specialists have to provide clear instructions on follow-up and how to act in case of complications.[6–8]

Previous studies have shown that breast cancer specialists follow patients longer than the guidelines prescribe, due to factors such as younger age, higher breast cancer stage, family history, treatment-related morbidity and on-going hormone therapy,[3,9] indicating that specialists have difficulty discharging patients to primary care.[9] This difficulty may be also explained by patients' preference for hospital follow-up and concerns among patients[10–12] and specialists[3,13,14] about the level of oncology knowledge and skills of primary care physicians. It is unknown if Dutch breast cancer patients aged >60, and treated with breast-conserving therapy, are actually discharged to their GP after 5 years of hospital follow-up. Furthermore, little is known about the implementation of breast cancer follow-up in general practice and whether this is accepted by Dutch GPs. Two studies have shown that 51% and 93% of Canadian primary care physicians were willing to accept exclusive breast cancer follow-up care immediately or 1–2 years after treatment completion.[15,16] No such studies have been performed in countries in Europe. Therefore, the present study explored (a) the discharge of breast cancer patients to primary care by specialists, at the end of hospital follow-up and (b) the experiences and views of GPs regarding transfer of follow-up to the primary care setting.

2. Materials and methods

2.1. Setting

A cross-sectional survey was performed in the context of the Dutch healthcare system, in which primary care has been at the centre for a long time. Almost all citizens are registered with a GP, who deals with 95% of health problems presented by patients.[17] Dutch GPs receive a substantial capitation payment for all registered patients.[17,18]

In the Netherlands, the current breast cancer guidelines recommend hospital follow-up for 5 years, including yearly mammography. After these 5 years, patients aged ⩽60 years have yearly follow-up visits and mammography appointments in the hospital. Patients aged >60 years who have undergone mastectomy are referred to the National Screening Programme for two-yearly mammography. Patients aged >60 years, and treated with breast-conserving therapy, are discharged to their general practitioner (GP) for yearly physical examination and two-yearly mammography.[6–8]

2.2. Questionnaire development

A self-administered questionnaire was sent to GPs working in the three northern provinces of the Netherlands (Drenthe, Friesland and Groningen). To develop the questionnaire, relevant articles concerning primary care physicians' views on their role in cancer follow-up care were reviewed.[13,15,16,19,20] Some questions in these articles were used for the present study and additional questions were developed. To improve face validity and content validity, the questionnaire and the cover letter were discussed with 10 GPs from different practices. The final questionnaire included personal and professional characteristics (Table 1), 10 items about current practice regarding primary care-based follow-up, five items about GPs' willingness to accept exclusive responsibility for follow-up and one item for additional comments and suggestions (Appendix). The final version of the questionnaire took ±10 min to complete.

2.3. Sample size calculation

The outcome used to calculate the sample size for this study was GPs' willingness to accept exclusive responsibility for follow-up earlier than 5 years after completion of active treatment. With a proportion of 0.5 (maximum variance) and a 95% confidence interval (CI), 385 GPs had to respond to the survey. Assuming a response rate of 40–50%, based on a previous study among Dutch GPs,[21] 769–961 questionnaires had to be sent.

2.4. Survey administration

Addresses from 960 GPs in the three northern provinces of the Netherlands were available, and all GPs were sent the questionnaire according to a modified version of the Dillman Total Design Survey Method.[22] Three mailing waves were done. The first mailing in September 2010 included a cover letter, the questionnaire and a post-paid return envelope (initial survey pack). GPs were asked to respond by post or fax. After 1 week, non-respondents were sent a reminder card. The remaining non-respondents received a reminder survey pack 3 weeks after the first mailing. The questionnaires were numbered so that non-respondents could be identified;

Table 1
Personal and practice characteristics of respondents ($n = 502$) and of all general practitioners (GPs) in the Netherlands.

	Survey (total)[a] *n* (%)	Survey[b] *n* (%)	National 2010[c] *n* (%)	*p*-Value[d]
Sex				
Male	332 (66.3)	318 (66.7)	5389 (60.4)	0.006
Female	169 (33.7)	159 (33.3)	3532 (39.6)	
Age in years				
<45	147 (29.5)	135 (28.4)	3219 (36.1)	0.003
45–54	192 (38.5)	187 (39.3)	3105 (34.8)	
>54	160 (32.1)	154 (32.4)	2597 (29.1)	
Practice experience in years				
<10	129 (26.2)			
10–19	158 (31.5)			
>19	205 (41.7)			
Practice setting				
Single-handed	159 (34.7)	152 (34.5)	1605 (18.0)	<0.001
Twin	133 (29.0)	132 (30.0)	2515 (28.2)	
Group/health centre	166 (36.2)	156 (35.5)	4801 (53.8)	
Region				
Drenthe	149 (29.7)	139 (29.1)	272 (29.2)	0.996
Friesland	189 (37.7)	184 (38.6)	360 (38.7)	
Groningen	163 (32.5)	154 (32.3)	298 (32.0)	

[a] Numbers do not add up to 502 due to missing data.
[b] Not including free-lance GPs ($n = 17$) and employment unknown ($n = 7$).
[c] Not including free-lance GPs.
[d] Chi-square test.

however, to ensure respondents' anonymity, these numbers were not used in the data analysis.

2.5. Statistical analysis

Descriptive statistics were used to summarise the items of the questionnaire. Personal and practice characteristics of respondents were compared with those of the entire GP population in the Netherlands.[23] Differences in characteristics were analysed with the Chi-square test. Logistic regression analysis was used to evaluate whether characteristics and current involvement in breast cancer follow-up were associated with GPs' willingness to accept exclusive responsibility for follow-up within 5 years after completion of active treatment. For all analyses, a *p*-value of <0.05 was considered to be statistically significant.

3. Results

3.1. Personal and practice characteristics

Of the 960 mailed questionnaires, 11 were undeliverable due to: an incorrect address ($n = 5$), retirement (5) and death (1). Of the remaining 949 questionnaires, 502 were returned, providing an adjusted response rate of 53%. The majority of GPs were male (66%), older than 44 years (71%) and in practice for $\geqslant$10 years (74%) (Table 1). They were almost equally divided between single-handed practices, twin practices and group practices/health centres. Compared to the entire GP population in the Netherlands, GPs in the survey were significantly more often male, older and working in a single-handed practice.

3.2. Current practice of primary care-based follow-up

In the year before the survey took place, one or more patients aged >60 years, and 5 years after breast-conserving therapy, were discharged to 22% of GPs ($n = 112$) for follow-up (Table 2). Some GPs noted that breast cancer guidelines are not complied with, and that patients are almost always followed up by their specialist for more than 5 years. According to 56% of GPs involved in follow-up ($n = 59$), transfer of this follow-up was communicated by the hospital. Nevertheless, several GPs mentioned that they received no clear instructions from specialists on follow-up and how to act in case of complications.

During follow-up of the patients most recently seen, the three most reported activities carried out by GPs were: asking the patient about symptoms (74%), performing clinical breast examination (73%) and requesting a mammogram appointment (63%). In this survey, 31% of GPs involved in follow-up ($n = 33$) used the current breast cancer guideline from the Dutch College of General Practitioners. The initiative to arrange follow-up visits and mammography appointments was mainly taken by

Table 2
Current practice of primary care-based breast cancer follow-up.

		n (%)
How many patients were referred back to you in the past year?	None	386 (77.5)
	One patient	30 (6.0)
	Several patients	82 (16.5)
If you have seen several patients for follow-up, please take into consideration only the patient that you have seen most recently:		
During the follow-up of this patient, I... (Multiple answers possible, $n = 104$)	Asked the patient about symptoms	77 (74.0)
	Performed clinical breast examination	76 (73.1)
	Requested a mammogram appointment	66 (63.5)
	Gave advice	28 (26.9)
	Emphasised the importance of breast self-examination	25 (24.0)
	Referred the patient to a specialist	13 (12.5)
	Other	11 (10.6)
Did you use the 2008 breast cancer guideline during the follow-up of this patient?	No	72 (68.6)
	Yes	33 (31.4)
Did the hospital communicate the transfer of the follow-up?	No	34 (32.1)
	Yes	59 (55.7)
	I don't know	13 (12.3)
Was the transfer of the follow-up clearly communicated by the hospital?	(Very) unclear	2 (3.5)
	Neutral	9 (15.8)
	(Very) clear	46 (80.7)
Who took the initiative to arrange follow-up? (Multiple answers possible, $n = 106$)	The patient herself made an appointment	95 (89.6)
	The general practitioner (GP) called the patient	10 (9.4)
	Other	7 (6.6)
Who keeps in mind that mammography has to be performed every two years? (Multiple answers possible, $n = 106$)	Patient herself	94 (88.7)
	GP	21 (19.8)
	Specialist in the hospital	6 (5.7)
	Other	6 (5.7)
	Nurse practitioner in general practice	1 (0.9)
Was your role during the follow-up of this patient clear to you?	(Very) unclear	21 (19.8)
	Neutral	27 (25.5)
	(Very) clear	58 (54.7)
How satisfied are you with your role in the follow-up of this patient?	(Very) dissatisfied	6 (5.7)
	Neutral	36 (34.0)
	(Very) satisfied	64 (60.4)

patients (90% and 89%, respectively). Some GPs questioned whether patients or GPs should be responsible for the organisation of follow-up. Furthermore, several GPs noted that the electronic medical record system they used was not suitable for planning follow-up visits. Of GPs involved in follow-up, 55% ($n = 58$) experienced their role during follow-up as (very) clear, and 60% ($n = 64$) were (very) satisfied with this role.

3.3. GPs' willingness to accept exclusive responsibility for follow-up

Of all GPs, 80% ($n = 374$) stated that their current contribution to breast cancer follow-up care was 'just right', while 32% ($n = 160$) believed that '*they should be involved at an earlier stage in breast cancer follow-up care*' (Fig. 1). In the survey, 40% of GPs ($n = 200$) were willing to accept exclusive responsibility for follow-up earlier than 5 years after completion of active treatment. In addition, 19% of GPs ($n = 93$) were willing to take over follow-up immediately or 1–2 years after completion of active treatment. Some GPs commented that they preferred shared follow-up alternately performed by GPs and specialists. Others stated that earlier transfer of follow-up should depend on patients' characteristics and views, and on specialists' views. Personal and practice characteristics as well as current involvement in follow-up were not significantly associated with GPs' willingness to accept exclusive responsibility for follow-up within 5 years after completion of active treatment (Table 3).

The three main barriers perceived by GPs to take over follow-up at an earlier stage were: patients' preference for specialist follow-up (65%), own oncology knowledge and skills (52%) and workload pressure (36%) (Fig. 2). With respect to their oncology knowledge and skills, 41% of GPs ($n = 205$) believed that '*they had the skills necessary to take over breast cancer follow-up at an earlier stage*', whereas 20% ($n = 97$) felt that '*they had the skills necessary to examine irradiated breasts to detect local recurrences and second tumours*' (Fig. 1). However, 61% ($n = 303$) stated that '*they were better placed to provide psychosocial support to patients with breast cancer than specialists*'. The three most useful tools perceived by GPs to take over follow-up at an

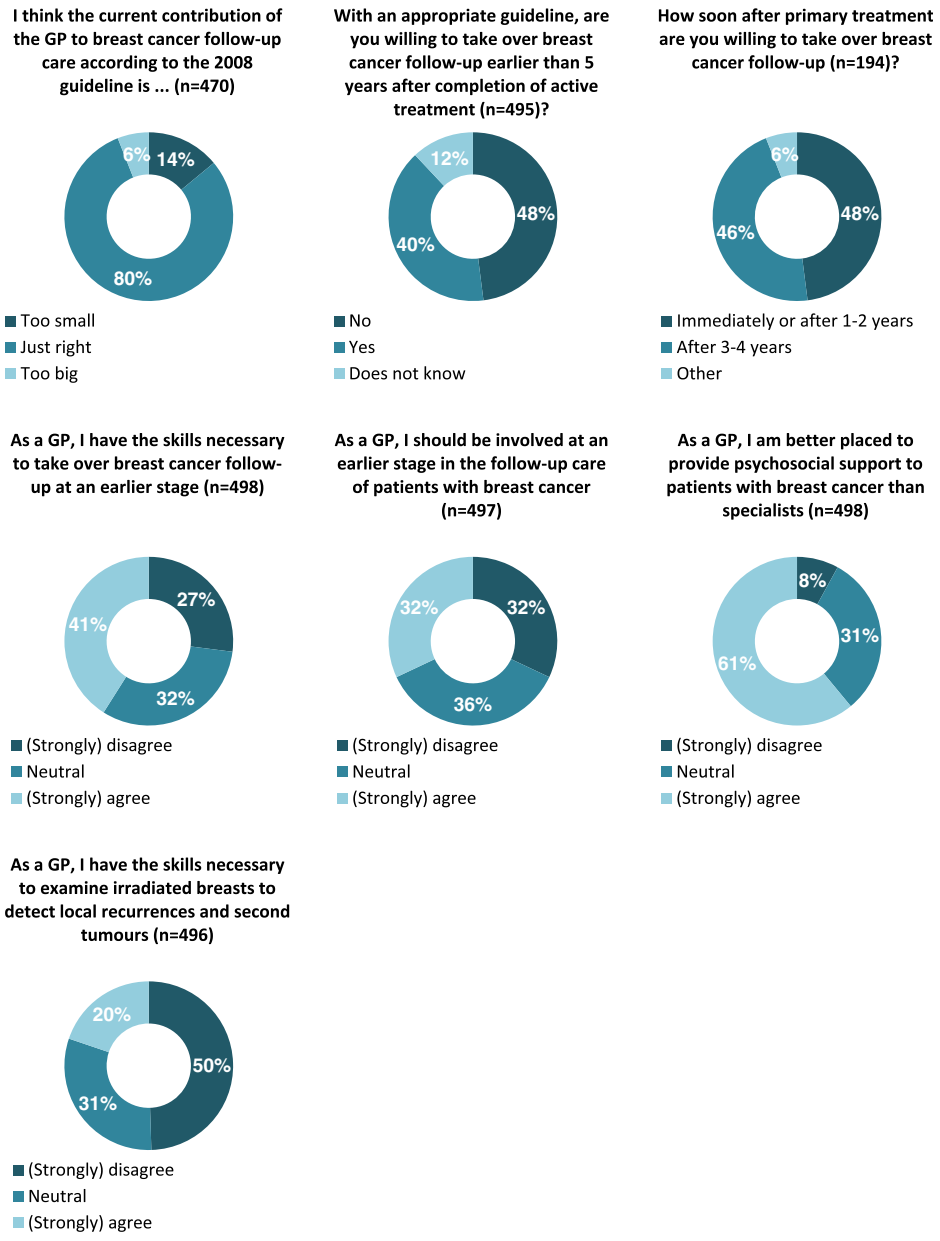

Fig. 1. General practitioners' (GPs') willingness to accept exclusive responsibility for routine breast cancer follow-up.

earlier stage included: a patient-specific letter from specialists with special focus on follow-up (74%), a refresher course in breast cancer follow-up (69%) and an updated breast cancer guideline from the Dutch College of General Practitioners (46%) (Fig. 2). In relation to these barriers and tools, several GPs commented that good collaboration with specialists, training of GPs in follow-up care and an automated calling system to support the planning of follow-up visits, would be helpful to take over follow-up at an earlier stage.

3.4. GPs' recommendations for current and future primary care-based follow-up

Additional comments/suggestions were given by 50 GPs. Their main recommendations for improving current and future primary care-based follow-up include the following: local agreements with specialists on follow-up policy, active discharge of patients by specialists, adequate supply of written discharge information, quick referral of patients to the breast cancer clinic when necessary, education and training of GPs in follow-up care and development of administrative tools to support the organisation of follow-up in general practice.

4. Discussion

In the year before the survey took place, one or more patients aged >60 years, and 5 years after breast-conserving therapy, were discharged to 22% of GPs for follow-up. According to 56% of these GPs, transfer of follow-up was communicated by the hospital. The

Table 3
Personal and practice characteristics associated with general practitioners' (GPs') willingness to accept exclusive responsibility for routine breast cancer follow-up at an earlier stage. Univariate odds ratios (OR) and 95% confidence intervals (95% CIs) were estimated with logistic regression analysis.

	Willingness		
	No ($n = 295$)[a] *n* (%)	Yes ($n = 200$) *n* (%)	OR (CI)
Sex			
Male	190 (64.4)	138 (69.0)	1
Female	105 (35.6)	62 (31.0)	0.81 (0.55–1.19)
Age, *n* (%)			
⩽50.0 years	155 (53.1)	90 (45.0)	1
>50.0 years	137 (46.9)	110 (55.0)	1.38 (0.96–1.98)
Practice experience			
⩽16.0 years	157 (54.3)	97 (49.5)	1
>16.0 years	132 (45.7)	99 (50.5)	1.21 (0.84–1.75)
Practice setting			
Single-handed	98 (36.3)	61 (33.5)	1
Twin	75 (27.8)	56 (30.8)	1.20 (0.75–1.92)
Group/health centre	97 (35.9)	65 (35.7)	1.08 (0.69–1.69)
Region			
Drenthe	80 (27.2)	67 (33.5)	1
Friesland	118 (40.1)	67 (33.5)	0.68 (0.44–1.05)
Groningen	96 (32.7)	66 (33.0)	0.82 (0.52–1.29)
Patients referred back to their GP			
None	228 (77.3)	155 (77.5)	1
One patient or more	67 (22.7)	45 (22.5)	0.99 (0.64–1.52)

Significant at $p < 0.05$ (*).
[a] Including 'responder does not know'.

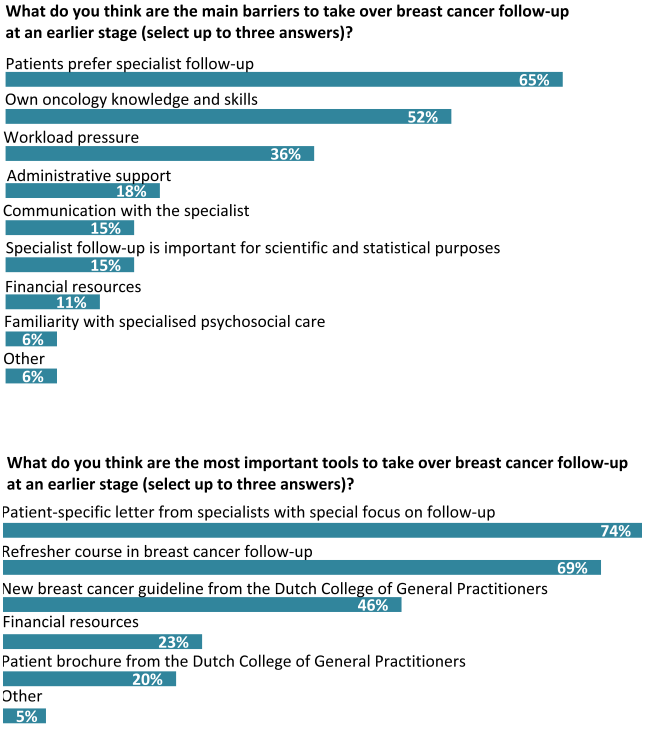

Fig. 2. Perceived barriers and tools to accept exclusive responsibility for breast cancer follow-up at an earlier stage.

initiative to arrange follow-up visits and mammography appointments was mainly taken by patients. In this survey, 40% of GPs were willing to accept exclusive responsibility for follow-up earlier than 5 years after completion of active treatment. Personal and practice characteristics as well as current involvement in follow-up were not significantly associated with GPs' willingness to accept exclusive responsibility for follow-up. Perceived barriers in current and future primary care-based follow-up included: communication with breast cancer specialists, patients' preference for specialist follow-up, GPs' oncology knowledge and skills and the organisation of follow-up in general practice.

The finding that patients were discharged for follow-up to only 22% of GPs in our survey might indicate possible non-compliance and/or non-familiarity of specialists with the current guidelines for follow-up. This is in accordance with previous studies suggesting that specialists have difficulty discharging patients to primary care.[3,9] We also found that only 31% of the GPs used the current breast cancer guideline from the Dutch College of General Practitioners during the follow-up of their patient. Previous studies have shown that clinical guidelines in general practice with low compliance rates were those requiring new knowledge and skills, not easy to follow, not compatible with existing norms and values

and not taking into account patient preferences, abilities and needs.[24–26]

In the literature, deficiencies in communication between primary care and specialist care are frequently mentioned as the major factor affecting the follow-up of cancer patients.[21,27] Only 56% of GPs involved in follow-up reported that transfer of this follow-up was communicated by the hospital. Good communication across the primary/secondary interface is necessary to guarantee that GPs as well as patients get clear instructions on follow-up and how to act in case of complications.[6,7] A major tool perceived by GPs to take over follow-up at an earlier stage included a patient-specific letter from specialists with special focus on follow-up (74%). Structured consultation and discharge letters, as well as clinical practice guidelines, are essential elements of survivorship care plans, which are useful instruments to facilitate communication among patients and healthcare providers.[4,27,28]

Willingness of GPs to accept exclusive responsibility for breast cancer follow-up has not been studied in Europe. Two surveys showed that 51% and 93% of Canadian primary care physicians were willing to accept exclusive breast cancer follow-up care immediately or 1–2 years after treatment completion.[15,16] In our survey, only 19% of GPs were willing to take over follow-up immediately or 1–2 years after completion of active treatment. However, higher percentages reported in the previous studies may be related to the fact that many Canadian primary care physicians already provide exclusive care to cancer survivors,[15,16] showing that a physician's self-confidence in this domain improves as the number of survivors in the practice increases.[29] Nevertheless, current involvement in breast cancer follow-up did not predict the willingness of GPs to take over follow-up in our study. Another explanation for differences in willingness between primary care providers in Canada and the Netherlands might be the relative influence of health care financing in these countries. Most Canadian physicians are remunerated on a fee-for-service basis, while Dutch GPs receive a substantial capitation payment for all registered patients.[17,18]

An important barrier perceived by GPs to take over follow-up at an earlier stage is the patient's preference for specialist follow-up. This is in accordance with other studies[30–33] showing that patients tend to prefer the most familiar situation.[31,32] Patients' preference for specialist follow-up,[25] together with guideline non-adherence among specialists and GPs, may explain the finding that patients were discharged for follow-up to only 22% of GPs in our survey. When follow-up is transferred to the primary care setting at an earlier stage, patients need to be well informed about the advantages and limitations of several follow-up models, so they can make an informed choice about their individual follow-up arrangements.[4,34]

Another barrier perceived by GPs to take over follow-up at an earlier stage involves their own level of oncology knowledge and skills. This belief was supported by other studies in which patients[10–12] and oncologists,[3,13,14] as well as primary care physicians[14] expressed concerns about the ability of primary care physicians to provide adequate breast cancer follow-up care. A useful tool perceived by GPs to take over follow-up at an earlier stage included a refresher course in breast cancer follow-up. Training and education of GPs and other primary care physicians seems essential to ensure that they have adequate knowledge and feel confident to provide follow-up care.[14,29] However, their self-confidence in this domain may also improve as the number of survivors in their practice increases,[29] as a consequence of providing follow-up at an earlier stage.

The organisation of follow-up in general practice was considered as a barrier in current and future primary care-based follow-up. An automated calling system integrated in the current electronic medical record systems (as well as other administrative tools) might be helpful to organise the follow-up in general practice. Another option may be the introduction of oncology nurses in primary care,[3] just as primary care nurses were introduced in Dutch general practice, partly to shift diabetes care from hospital to primary care.[35] Nevertheless, as the initiative to arrange follow-up visits and mammography appointments was mainly taken by patients in our study, the question arises whether follow-up should be patient-driven or primary care provider-driven.[36] Recently, Blaauwbroek et al.[37] developed a (web-based) survivorship care plan for adult survivors of childhood cancer and their GPs. This plan was greatly appreciated by the survivors, who had become more aware of potential risks of health problems and of the benefits of follow-up.

Our survey explored whether Dutch breast cancer patients aged >60, and treated with breast-conserving therapy, are actually discharged to their GP after 5 years of hospital follow-up. Furthermore, this the first study in Europe to evaluate the implementation of breast cancer follow-up in general practice and the acceptance of this follow-up among GPs. The response rate was comparable to that observed in another study among Dutch GPs.[21] GPs in our study were significantly more often male, older and working in a single-handed practice than all Dutch GPs.[23] As we found that these characteristics were not associated with GPs' willingness to accept exclusive responsibility for follow-up, we believe that our findings provide important insight into the discharge of breast cancer patients at the end of hospital follow-up and that these are also relevant to primary care providers in other countries.

Based on the results of this study, primary care-based follow-up might be improved if breast cancer specialists discharge patients more actively to their GPs.

Survivorship care plans are needed to facilitate communication across the primary/secondary interface and with patients. Training of GPs and developing administrative tools may be helpful in arranging follow-up care and using guidelines in general practice.

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No funding was received for this study.

Conflict of interest statement

None declared.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.ejca.2013.01.016.

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